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ABSTRACT

In a consideration of limited funds for services to disabled persons, the author distinguishes the "truly handicapped" from "handicapped victims" (characterized as afflicted persons who receive few or no services) and the "mildly handicapped" (including educable retarded, learning disabled, and mildly emotionally disturbed). He proposes a model incorporating a competitive market for services to handicapped students. The amount of funding received by mildly handicapped students is questioned and overprotection of truly handicapped students is cited. The author suggests a change in the operation of special education in which families would receive voucher money to procure the services they deem most appropriate. Informal alliances among handicapped persons, as observed in developing nations, are advocated. There are two groups of "losers" in the present system: the mildly handicapped, who receive more stigmatization than help; and the handicapped victims, who society removes from the definition of handicapped because of a moral judgment. (CL)

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PROVIDING SERVICES TO THE HANDICAPPED IN TIMES OF BUDGET RETRENCHMENT

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Part 1: Redefining the Handicapped Population

It is important to agree upon who we are referring to when we apply the term handicapped. When people talk about a handicap they often have rather definite, yet nearly unconscious ideas about what they mean.[1] I remember two chance encounters in a small Ecuadorian pueblo that helped me understand how arbitrary this term could be. In the first, I saw an ancient blind man humbly dressed, but not in rags, walking through the adobe streets leading and being led by his cane. When he met people they contributed to his pouch which hung from his neck. I felt at once sympathetic and understanding. A few blocks down the way, however, I saw another man so drugged by alcohol that he lay as immovable as the ancient cobblestones beneath him. Toward him, I felt disgust and anger. Later, I asked myself, which one of these two people is handicapped? In times of budget retrenchments, who should receive services?

It has become apparent to me that the handicapped are a very diverse population. They are in part, the product of the images and value judgments non-handicapped people have of them. We, the non-handicapped, are unequivocably put at ease to know that some disabled people are receiving help because we perceive that these people are the products of an accident, the ultimate in bad fortune. We reach out to them because we know they haven't caused their handicap; our image of them is drawn from pity and our discomfort eased when they are given help. Thus, we can easily accept the notion of services given to the blind man in the Ecuadorian pueblo. This category of handicapped people who

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[1] 1981 was the International Year of the Disabled Person and the author was appointed by the United Nations to represent them in South America. He will be drawing from these experiences in this paper.

are perceived as victims of fate, I will call "truly handicapped."

Other victims such as the drunken Inca Indian lying on the cobblestones, because they are seen to be responsible for their disability, are excluded from the term "handicapped" and receive few or no services. These disabled people who, nevertheless, are limited and afflicted, I will call the "handicapped victims."

Then there is another group whom we can call the "mildly handicapped." In this group are the educably retarded, the majority of the learning disabled, and the mildly emotionally disturbed. I will point out that these people are only questionably handicapped and yet they receive, relatively speaking, an inordinate amount of services.

Another important distinction which runs through all three categories is the degree to which the handicap is visible to the public. There are visibly and non-visibly handicapped people in all three of the handicapped categories. In the case of the visibly handicapped, the disability is public, such as spasticity. The disability of the non-visibly handicapped is private, the affliction known only to himself and the people whom he tells. An example in this group is epileptics. The reason I bring the visibility of the handicapped up is because the reactions these two groups receive from the public are quite different. This was brought to my attention by a 30-year-old student of mine, who appeared to an outside observer to be a youthful and attractive woman, but whose heart was quickly rejecting its third pacemaker. She was unable to receive any help because of her handicap, while the more visibly afflicted easily received aid. Thus, she had to obtain letters from doctors, plead with authorities, and finally break down in tears before she was granted a special parking sticker; without this she would have to walk to campus, something that could be deadly for her.

The worlds of the visibly handicapped and non-visibly handicapped are quite different; each has its own problems and its own psychology, and each receives different messages about what to expect from the non-handicapped world. When a handicap cannot be seen, many people withhold the sympathy they are so willing to give to the publicly afflicted. Thus, part of the expectations imposed by the non-handicapped is that disabled persons must express some outward sign of the affliction. In this way, the handicapped person must give testimony to his own disability before being able to expect compensatory treatment. Like coral fish who develop coloring patterns for stylized interactions of courtship and anger, the handicapped must display himself in order to make himself understandable, and thus be given the handicapped status.

Part II: The Proposal

In order to solve the problem of the 80s, the problem of more special interest groups demanding services because they feel they are worthy of receiving a piece of the diminished pie, I propose (1) a zero reject model from the regular classroom, and (2) a competitive market for services to the handicapped. A zero reject model would mean that only children who are legally adjudicated as criminal should be released from attending regular classrooms. This would, in effect, be supporting the intent of "mainstreaming" by insisting that all children who are not disruptive be included in their schools and society.

If we want to label children handicapped they could, at the time they receive this label, also receive a voucher and be entitled to use it either within the public school, or in choosing a private provider. The voucher would be used to increase academic skills; those receiving it would be eligible for services at any time in their lives until they achieve a certain preordained level.

The effect of putting the focus on skills rather than on the handicapping condition(s), when combined with giving parents the option of choosing private providers, would establish a competitive marketplace centering around the goal of encouraging certain capabilities and not simply the remediation of a handicap. Less emphasis would be on diagnosis and categorization; less regulation would be required and administrative and capital costs would be reduced so that students would receive more direct aid for the same amount of money.

This proposal would change the balance of power. Currently it is to the advantage of a teacher to have all the children that she does not want in her classroom placed in special education; and, it is to the advantage of the special education establishment to encourage this. The parents, on the other hand, are the disadvantaged in the current system because they have little choice among the services provided. In the program I propose, the situation would be reversed because parents would bear the extra cost of educating their labeled child directly and would be able to choose between private and public services as the burden would shift to the teacher and school system because both would lose money each time they put a child in the special classroom.

Part III: How the Three Handicapped Groups Would Make Do in Times of Retrenchment

Although services to the mildly handicapped population have been a boon to the professional worker by providing many more jobs, they have at the same time done a disservice to the clients, who suffer from the label without a corresponding gain from the additional attention.

The other day I spent a morning in a special education class with 15 children from eight to 10 years old. They were adjudicated through the school system's network of professionals as mildly learning disabled and educably mentally retarded. Not one of the children showed any signs of neurological defects

that could be physically demonstrated, either by observation or from electroencephalogram. However, they were all receiving a curriculum devised to improve their neurological functioning. They were asked to draw outlines of shapes, to color between lines and to copy forms using their large and small muscles. These tasks prevented them from rigorously drilling in academic areas. Yet, on the playground, I had seen the children play informally with an intensity to excel that was almost in complete contrast to the atmosphere of the classroom where they were being treated as helpless, like the truly handicapped. Once the children started working at their tables, the teacher furiously began to copy lesson plans and reports, which she told me her supervisor said were necessary because of school policy and governmental regulations. Meanwhile, the aide was going from child to child helping them with their coloring, using the glossy well-packaged materials that were made for profit by private business.

As I sat in the comfortable modern room, I began to question the assumptions about who the mildly handicapped are and the amount of money they receive. The cost of a special education room is double the cost of the regular classroom because in addition to the special curriculum materials and the modern classroom, the team of special education personnel includes the teacher, her aides, its own diagnosticians, supervisors and administrators. When these professionals combine in force to tell parents that special education for their children is the best thing for them, the professional establishment unwittingly applies the imagery of the truly handicapped to the mildly handicapped. The effect of this is to create a moral momentum that forces parents and the public to equate a refusal of the advice of the professional team with a refusal to help the helpless and the truly handicapped.

Since on the average only about 10 percent of the students placed in special education ever return to regular classrooms, it is important to assess what

happens to the children who receive special education for the mildly handicapped. The results of research are mixed, but they seem to show that children in special placement do not improve academically over their counterparts in the regular classroom. On the other hand, investigations point out that the mildly handicapped, because of their special placement, develop poor se'f-concepts, feel isolated from their friends, and when leaving school are curtailed in their economic opportunities.

Admittedly the mildly handicapped need services, but to place them in special education is to put them into the context of the truly handicapped. This confuses the issue, which I believe to center where the school is concerned on the lack of skills. As children become handicapped in the eyes of the school, they receive a judgment about their character that is at the same time highly professionalized and moralistic.

Often the well-intentioned special educators who are conditioned by their own education to think they are saving the needy and helping the truly handicapped lack the political sophistication to understand what they are doing to the lives of their mildly handicapped students.

At the same time, special educators are overly protective of the truly handicapped, often providing inappropriate services. I estimate that for each truly handicapped child born 25 people are affected: parents, certain relatives, close friends, neighbors, etc. These people are what I call naturally, or ecologically involved with the well-being of the handicapped person. Their life's circumstances make them available, maybe even in need of helping. Each of them have their own unique abilities and could be employed for specific purposes without receiving professional wages or working in separate facilities. I have a student now who is without the use of his legs. He paid his university tuition

by painting address numbers on street curbs, partnering a cousin to help him carry the materials. These types of relationships are not fostered in a society that regulates, through professional lobbies and legislation, services in expensive buildings given exclusively by salaried professionals. By giving voucher money directly to the truly handicapped person or his family, those truly handicapped would have the opportunity to form and sustain informal alliances that could be beneficial to forming mutually supportive relationships.

I encountered a good example of an informal alliance that was mutually supportive in Haiti where I talked with a blind peddler who was selling fruit on a street corner. He told that because of his blindness, people were willing to pay slightly higher for his fruit than they would in the stores. He went on to tell how one day he had been approached by a "gamine." A gamine is an orphan who refuses to accept the special services provided by the state and instead lives on the streets. The boy, he told me, had offered to bring the apples to him and help him get from place to place in return for a percentage of the profits. As a result of the two of them helping each other, they both lived better than either of them could have alone. Many handicapped people, like these two in Haiti, have found ways to support themselves either by capitalizing on making their disability an asset or by finding mutually supportive relationships with other handicapped people. The ingenuity and cunning of these few disabled people could be important to the welfare of many of the truly handicapped in the United States who would be helped by learning how these capable disabled persons are able to help themselves.

Recently I was traveling on a subway in New York when I was solicited by a blind beggar in a wheel chair who was being pushed through the subway by a male friend. This young man was about 30 years old. From the waist up he was very healthy looking with stylish glasses and hair that seemed to be professionally

shaped. I sensed from the demeanor of his upper torso an air of intelligence and competence. This was in contrast to the lower part of his body. He had neatly folded his pants over his lap to reveal his naked and deformed legs. From one leg hung a plastic cord like the ones used in hospitals for transfusions. I was confused because the two halves of his body presented such contrasting images that I was not sure who he really was. Was the apparatus of his lower extremity a misfortune worthy of sympathy or was his upper torso evidence of a truly competent person manipulating the public's sympathy in order to earn an easy living?

Those who favor the usual program for the truly handicapped would send this man to a vocational school where, if he were successful, he would be placed in a sheltered workshop to engage in repetitious and routinized work. I saw a man very much like this man in a sheltered workshop in the Dominican Republic; that is, the lower halves of the two men were the same, the blindness identical, but instead of an intelligent and entrepreneurally confident expression as I saw on the face of the man in the subway, I saw on this second man an expression so vacant that I was actually more impressed with the depression on his face than the fact of his blindness.

But, even with the comparison of these two men in mind, I could not deny to myself that I was taken in by the argument calling for increasing allocations for the truly handicapped. The pull toward providing help is so strong that I felt hostile to the subway beggar; my attitudes toward how he presented his handicap prevented me from seeing that he was begging because he could earn a living on his own terms and on his own time. When I examined my feelings I realized he was living without receiving professional care and without having to submit to the fact that he was as incompetent as his lower-half suggested. Instead, he was living more like his upper torso--freely, creatively, and intelligently.

One result of receiving the standard professional treatment is the sacrifice of the few advantages there are to having a handicap. Handicapped people in countries where there are almost no formal programs for them often live because of their handicap, not in spite of it. Less developed countries could teach us a lesson in these times of retrenchment. Many truly handicapped people who have rejected professional help function quite competently.

The largest categories of "handicapped victims" which I define as those who are held responsible for their disability are the drug and alcoholic abusers. The psychology concerning the causes of drug addiction and alcoholic abuse is rapidly changing. It was once thought that substance-abuse problems were based on the failure of the offender to control his own immoral inclination. Now the notion is that these problems are the result of faulty biochemistry. This development changes the locus of blame from the person's character, something he can or should control, to the person's biochemistry, something given and unchangeable. At this time, both society and the professional worker accept some of both points of view. Only when we accept the later and emerging view can we see the drug offender and alcoholic abuser as handicapped. This is because central to the concept of what a handicap is, is the idea that a handicapped person is a victim of fate and does not contribute to his own disability. This is in part why handicapped people must display their fateful affliction to the public in order to get the rights of a handicapped person. Through a visual display of a handicap, the public is able to check the degree to which it is a misfortune worthy of sympathy.

There is a choice to be made, then, when we think about the handicapped, a choice which is at once moralistic and dependent on our ability to accept people as victims. Once we begin to accuse, even imperceptibly, then we are likely to eliminate the accused from the handicapped.

Thus, a person who meets bad times due to some element of his own personality will not be considered handicapped. This is an unfortunate problem affecting all of us. For example, a man I know has been diagnosed both diabetic and manic depressive. This man overspend his family's income, abuses his children and wife, and wreaks havoc on nearly everyone he knows. From those behaviors we are likely to see him with disgust and certainly not as handicapped. If we saw him inject insulin in his body or take lithium, however, we might feel sorry for him and could conceivably give him the status of a handicapped person.

How far can we go with this? We can accept behavior which leads to excessive self-doubt and incapacitating action as "handicapped," but when neurosis leads to criminal behavior we are likely to call for castigation. Criminal behavorior in a way is the opposite of a handicap. This explains my reactions to the subway beggar. I was not sure who he really was, how I should feel about him. As I felt my attitudes range from sympathy to anger, I felt like an air bubble in a carpenter's level, trying to find how I should accommodate my feelings, wondering if I should make them morally appropriate to either a handicapped person worthy of charity, or a beggar taking obnoxious presumptions. Was he a victim or a manipulator?

Handicapped victims teach us that we have a moralistic attitude toward the concept of the "handicapped." This explains why some groups of people in small trouble (the mildly handicapped) receive a great deal while others (the handicapped victims) receive almost nothing, even though they might be in great need. We all make judgments which tend either to condemn or sympathize with behaviors that on the surface, and out of context, we find abhorrent. To see someone we love or respect do something we find obnoxious or destructive is to be put into the position of a religious leader who has to evaluate the actions of people in order to pass judgments. To the extent we commit outselves to relationships

with other people, we are all in this boat together. Surely there must be a humane way of solving this dilemma other than excluding whole groups of people by general policy. It would be better to deliberate over individual cases, as painful as that might be.

Conclusion

We have seen there is a choice to be made when we use the term handicapped. To those people who we feel are the result of bad fortune, we easily turn our efforts; those unfortunates who we feel have caused their own demise, we ignore. In the past two decades when resources to the handicapped have increased, instead of helping many who are truly needy, we have created a group of mildly handicapped who now receive a great deal of money even though the efficacy of the programs is questionable. For all groups we label "handicapped" we have a system of programs so that the actual amount of aid they receive is filtered through an expensive team of professionals, materials, and capital outlays. Only a small percentage of the money given to the handicapped is actually received by them. Inherent within the good intentions of the professional establishment is a certain naivete which subtly promotes a faith in the ability of the handicapped to help themselves by finding their own benefactors and by forming mutually supportive relationships. I am left with the belief that the major winners of the current policies are the professionals who maintain their employment and that there are two groups of losers, the mildly handicapped who receive more stigmatization than help, and the handicapped victims who we remove from the definition of handicapped because of a moral judgment.